Social Research Report – December 2015

1- Introduction

In December 2015, Médecins du Monde (herein MdM) requested the elaboration of a social report aiming at informing the obstacles of access of mental healthcare in Greater Cairo.

As such, MdM team proposed the following research question:

> ***What are the barriers in accessing mental health services by the most at-risk populations in Greater Cairo?***

The objectives of the report were to analyse common understandings related to mental health, mental health services, and the project's target groups and to generate conclusions and recommendations for better integration of people at-risk within their communities. The conclusions of the report will be used to inform an effective advocacy strategy for improvement of mental health services, and improvement of access to these services and to regularly guide and inform the project activities.

The pilot study conducted in September and October 2013 set up a good foundation to elaborate the social research. The pilot helped to understand the knowledge, use of terms and definitions that were already familiar to MdM's partners and communities. Community sessions were more difficult to conduct and communities showed little interest to the proposed topics. Reasons behind could be that communities, on the contrary to NGO's workers, showed little knowledge regarding what it is mental health, how to identify mental problems, the ways to deal with it or where to seek advice and services. Communities' general understanding was that bad mental health conditions are linked to a bad person and feelings of punishment and pity were the emotions that guided how communities manoeuvre members that show conducts not appropriate or tolerated. This pattern was also confirmed this social research report.

However, with regard to NGOs' staff, they deal on daily basis with the different target groups and constantly remark poor mental health statuses in most of the clients, which mainly shows as fear, anxiety, inability to solve problems, violence, lying, mistrust, depression, isolation, etc.

Also, the pilot study showed that NGOs attribute great importance to the link between roots causes that brought their clients to their premises and their mental health status. All NGOs remarked the family and community failure to deal with their clients and violence against women and children –including reference to failure of the law and state's protection mechanism- were key to the mental health problems found in their clients. The third most highlighted aspect was the very impoverished economic situations, and financial problems noted at the households of their clients. Also, peer pressure and bad influence was mentioned following the three above. Finally, NGOs' workers also referred to

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negligence, lack of space, isolation and religious and sexual education as factors that affect the mental health conditions of their clients.

However, NGOs' staff answers referring to the consequences of mental health disorders were very diverse and less aligned, including some misconceptions such as for instance that mental health problems could lead to an 'invert child'. Still, there was the common understanding that marginalisation from family and community, and violence were common consequences. **The resources and management of cases pointed at some shortfalls that NGOs may not be fully aware off. Activities led by target groups, spaces available for them, focus on positive cases, group therapy and clear protocols for referral and follow-up were rarely part of their work**.

Finally with regard to **stigma**, there were common myths that NGOs could agree upon. Some of them were: **people living with mental health problems cannot recover**, they are second-rate persons, they are dangerous, bad people deserve mental problems, etc.

The pilot concluded that having sessions with each of the NGOs to better understand their capacities, present services, forward aims and things they wish they could have to provide a better quality of their job was highly recommended.

On this basis, different sets of data collection methods were put in place to further understand the preliminary findings highlighted in the pilot study. This report convey the findings of these different methods.

This final report was requested and supervised by MdM- Egypt General Coordinator Ms Clara Di Dio and MdM –Egypt Medical Coordinator Dr Sally Toma. It counted with the collaboration of Ms Theodosia Rossi, MdM Egypt technical team and interns and the unvaluable contribution of MdM partner NGOs: Banaty, Basmat Amal, El Shehab and Cewla.

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2- Background

a) MDM Egypt project's briefing and strategy:

MdM has been present in Cairo since 2005 with two projects:

- "Health right promotion for Children in Street Situation in Great Cairo", funded by Drosos Foundation (2009 to 2012);
- "Access to Reproductive health care for girls living in the streets of Cairo" funded by Drosos Foundation (2005-2008);

Through the experience gained in these projects, it was clear that children living in street situation had particular mental health patterns related to their marginalized and risk living conditions. Also, the discussions with NGOs, and other experts in the field, particularly in the Ministry of Health (MoH), underlined not only the specific needs on mental health for vulnerable populations, but as well the lack of efficient services in the community and in primary health centers. To address this gap, MdM designed a third intervention titled **'Improvement of access to mental health services among the most at risk populations in Greater Cairo'.**

The **project's target group focused on most at risk populations** (MARPS) like victims of violence, children living in the street, people living with HIV/AIDS, and persons with disabilities. These were populations identified as in greatest need of mental healthcare and psychosocial support (MHCPSS). Moreover because they are also highly stigmatized groups.

The project then established as starting point the following baselines:

- MoH will allocate adequate resources to implement the shift towards community care.
- MoH will provide specific training for health professionals and other practitioners surrounding the care of mental health patients: social workers, nurses, PHC centres, health visitors and other community actors.
- Stigma surrounding Mental Health is recognized to be a main barrier preventing access to information and to create positive environments that foster rehabilitation and reintegration.

Accordingly it set up **three main objectives**:
Objective 1: Mental Health services are available and effective in 7 PHC centres in Cairo
Objective 2: Capacities of the civil society to work with vulnerable population are improved
Objective 3: Effective and sustainable resources are allocated to implement efficient Mental Health policies

As a result, **access to services and stigma around MARPS and mental health were the two main angles that the project was addressing**.

In this regard there is a severe lack of mental health care services in Egypt, despite the fact that mental health issues impact a significant proportion of the population (16.93% of adult population according to a 2009 national survey).

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The primary issues identified by MdM are the lack of integrated services and support programs at the community level and the lack of mental health care services in the primary health care system, particularly in marginalized and deprived areas. MdM's general objective is to improve access to mental health services among the most at risk populations in Greater Cairo, with a focus on improving mental health care access in both community and primary health care services.

In parallel, the National Mental Health Program, 1996- 2003[1],(which one of its aims was to decentralize mental health care and community care in various Egyptian governorates in addition to recruiting mental health staff), is outdated and efforts to implement it have been inadequate and insufficient. Moreover, other improvements that need to be included is the operationalization of the "Law for the Care of Mental Patients" following Egypt's ratification in April 2008 of the UN Convention on the Rights of Persons with Disabilities.[2] Finally, since 2011 Egypt is going through an acute socio-political and economic crisis that have displaced, -if not completely erased-, debates that directly affect the operationalization of mental health policies and budgets, although precisely because of the crisis, mental health services could be highly needed.

Stigma around mental illness is a significant issue and continues to be prevalent even in high-income countries with quality healthcare systems.[3] This stigma impacts individuals with mental illness and their families, as well as the general field of psychiatry.[4] MdM has identified stigmatization in health facilities and community environments as a major issue in relation to the rehabilitation and reintegration of at-risk populations. Understanding and reducing stigma is, therefore, key to MdM's general objective of improving access to mental health services in Greater Cairo.

On 12 March 2013, the pilot study conducted by MdM with 16 staff members working with individuals with mental illnesses pointed that staff members often incur in dynamics that reproduce stigma. The study also included data gathered during the needs assessments of partner NGOs in April 2013, and their re-assessment in August-September 2014.

b) Mental Health in Egypt: Policy and Services

Psychology arrived in Egypt in the early 1900s and the discipline was formalized with the establishment of a department at Ain Shams University.[5] There are 17 medical schools in Egypt, all with psychiatric departments, offering diplomas of neuropsychiatry, as well as master's and doctorate degrees in psychiatry.[6]

[1] (EIPR 2015; WHO and Ministry of Health 2006)
[2] (MDAC 2008)
[3] (Chang et al. 2014)
[4] (Sartorius et al. 2010)
[5] (Mohamed 2012; Amer et al. 2015)
[6] (Ahmed Okasha 2004)

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Egyptian psychologists have primarily followed Western models.[7] Psychological practice continues to focus on the individual, with psychotherapy serving as an important tool that aims to facilitate adaptation and to address the manifest stress or disability.[8] Still, in practice access to psychotherapy practice is very limited. Community psychology remains underdeveloped, slowed by reliance on Western psychiatry and the medical model.[9] A master's program in community psychology was created at the American University in Cairo in 2010, but the program will most likely be limited in impact to civil society practice.[10]

A number of problems face the discipline of psychology in Egypt. Universities are struggling economically, publications do not provide adequate normative data about local populations for use in comparisons, tests and textbooks are often translated from the Western context, and many subspecialties are underdeveloped or nonexistent.[11] There is also a lack of well-defined job opportunities for psychology graduates and significant disciplinary stigma.[12]

In recent decades, mental health policies and programs have been aimed at promoting available services and transitioning from institutionalization to community-based treatment.[13] From 1975-1981, WHO worked in Egypt to expand the range of mental health services and to integrate mental health into the primary care system.[14] In 1986, the national mental health program aimed to implement these aims in collaboration with the nongovernmental sector.[15]

The 1978 mental health policy aimed for "improvement of the mental health of individuals through the provision of services to those who need it and through the provision of community care and family support."[16] In 2003, the policy was amended to include objectives of: reforming mental hospitals to offer more comprehensive treatment, increasing community services, and incorporating mental health into the primary care system.[17] The National Mental Health Programmes of 1991-1996 and 1997-2003 aimed to incorporate mental health into primary health care by training primary care physicians and raising public awareness of disorders and referral routes.[18] In 1997, a 10-point mental health work plan was put forward, with the first point being the provision of comprehensive mental health services, incorporation of mental health into the primary care system, and the introduction of emergency services.[19] Little of these reforms were implemented and as mentioned above, 2009's Law and the full operationalization of the UN Convention has yet to be reinforced.

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[7] (Amer et al. 2015)
[8] (Amer et al. 2015; Ahmed Okasha 2004)
[9] (Amer et al. 2015)
[10] (Amer et al. 2015)
[11] (Mohamed 2012)
[12] ((ibid)
[13] ("Mental Health Situation and Services in Egypt" 2015)
[14] ((ibid
[15] ((ibid)
[16] ((ibid)
[17] (ibid)
[18] (Ahmed Okasha 2004)
[19] ("Mental Health Situation and Services in Egypt" 2015)

Egypt does not have adequate financial and human resources for mental health and lacks collaboration between the health sector and civil society.[20] The financing as of 2006 was not enough to cover the costs of mental health services, NGOs, community leaders, and international organizations provided support.[21]

Egypt lacks adequate community-based, preventative, and aftercare services.[22] There are 62 mental health outpatient clinics, with only one offering follow-up services for patients in community-based treatment, and no residential facilities.[23]

Efforts to incorporate mental health into the primary care system have produced few results.[24] As of 2006, only 5% of primary care physicians participated in required courses on mental health and under 20% were familiar with the protocols needed to refer patients to mental health professionals or prescribe psychiatric medication.[25] Finally, despite the commitment of the MoH to move towards a community base model, Mental Health Care is largely, if not almost uniquely, based in a mental hospital model.

3- Methodology for this report and objectives:

In December 2015, the incumbent was asked to review and assemble all the data that was collected with the purpose of issuing what was tilted 'MdM-social report'

Due to staff changes in the office in Cairo, the work needed to accomplish this task was left unfinished with a number of shortfalls that had to be detected, amended when possible and considered in the conclusions for future research.

Based on sound knowledge from the staff working in the Cairo's office at the time and a pilot conducted in September and October 2013, a research question and a number of data collection methods were proposed.

This consultancy has focused on: a) re-establishing a coherent research line; b) revising and filtering the data produced that can inform the research line; c) arriving to conclusions and shortfalls with the existing data and; d) suggest amendments to the research team in MdM office to correct these shortfalls for future research.

a) Data collection methods' update

Literature review: At the time that this consultancy started, two literature reviews were already finished. As per the documents received, 'literature on various issues related to mental health in Egypt is extremely limited in quantity and scope. Empirical research is particularly lacking and insufficient, at least that

[20] ((ibid)
[21] (WHO and Ministry of Health 2006)
[22] (Ahmed Okasha 2004; "Mental Health Situation and Services in Egypt" 2015)
[23] ("Mental Health Situation and Services in Egypt" 2015)
[24] (ibid)
[25] ((ibid)

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which is accessible and available online'[26]. The first review revolved around mental health in Egypt, the second one had a particular focus on stigma. Both literatures reviews have been partially integrated in the main body of this research and the incumbent reviewed again key articles that were aligned with the research questions and the data available.

Desk review: This was added in the last phase in December 2015. The review of program documents from different organizations (this includes studies that can be used to establish proxies) helped to understand which are the research needs and what is the data that can be extracted from the resources available at the MdM program and other partner organizations. With the purpose of assessing questions of access, it was also included a review on primary health care facilities with regard to sexual and reproductive health services within the Health Sector reform. Due to the nature of a very centralized health system, parallelism with the Mental Health Services could be drawn.

Interviews: The initial proposal considered semi-structured, open-ended interviews with participants over the course of 6-12 months. In principle the interview questions aimed at focusing on perceptions of mental health and accessibility of mental health services for target groups

- Key informants
- General populations
- Target groups
- People working in target groups
- Families of target groups

Focus groups:

- General Population/Communities
- Target Groups
- People working with target groups
- Families of target groups

14 interviews to children living in street situation, 2 key informants and 4 staff working with children in street situation were integrated in the report. These were complemented with 7 interview reports. Eventually, if there is more time available the remaining interviews could be integrated in future reports. These interviews are: 10 interviews with people at risk of HIV; 11 interviews with people with special needs. As per the data received, there were not records on focus groups discussions.

Ethnography:

Ethnography was another source of data collection which consisted in notes taken by the interns of MdM with observations in communities, conferences, workshops, etc, in addition to field visits to NGOs, PHCCs, and hospitals. A sample form was prepared to guide the observations. 13 ethnography reports related to 13 MdM events (trainings, self-esteem activities with children and a theater play for children with special needs) were included in the review.

[26] Quote from the literature review as part of the data received for this assignment.

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Media Analysis: A media analysis consultant was assigned to look into the representation of mental health in Egyptian media. Unfortunately, due to changes in the MdM staff this assignment was never finalized and the data received was incoherent.

Participants in the research: MdM Egypt staff, Partner NGOs and Research Assistants/Interns, Research Consultants. For the purpose of the report, the incumbent also conducted several meetings with MdM staff, which dealt with the research scope and sound knowledge from their experiences.

Limitations:
As a result of the variety of methods used to elaborate this report, the main approach has been to contrast the findings of each of the methods among the rest. This is a triangulation between different information, aiming at seeding light into silences, gaps, contradictions, assumptions, etc. that could enlighten further research and inform programme decisions.

The main limitation encountered during the revision of the data available, was that the methodology did not include the assessment of public services, neither the medical staff working there. This was due to MoH's delay in the signature of the MoU which would have granted access to PHCUs.

With regard to **sampling**, the original research proposal already stated that it was going to be difficult to guarantee a representative sample. Instead it was proposed that the accessing technique would be through the partner NGOs. This had the consequence that the interviews only included people already labeled as part of the MARP community and receiving services from those NGOs, **so assessing perceptions of stigma from the community was not collected in the interviews (also because focus groups were not conducted)**

Ethnographies were a good source of data to understand dynamics and preconceptions of NGOs staff that will reproduce and perpetuate stigma. **In the future it will be important to tailor a specific questionnaire to interview NGOs' staff based on the findings of this report**, this core group will bring important data into the two angles of this report: access and stigma.

With regard to the **questionnaires, there was a gap between the research questions and the guided questionnaire** because there was only one kind of questionnaire that was used for MARPS and staff alike. **In the future it will be necessary to tailor different questionnaires addressing access and stigma for the different target groups: staff, MARPs, community, therapist, etc.**

The questionnaire was good at keeping **interviews short and with clear questions**, which helped to systematize data. However questions need to be fine-tuned and separated by ideas. Therefore, it will require an engagement with the participant in different occasions to treat different topics. This will be the added value of using the NGO network for research.

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Interview-questions focused on understanding perceptions of mental health by the participants with regard to three degrees: the participant, someone that they know, and someone that they do not know. Questions that could lead to specific events or dialogues that could explain **how the participant suffered from stigma or how he/she perceives it were missing.** Also, there were **not questions with regard to how the participant got access to the facilities** were he/she was being treated neither specific details about background that could seed some light into societal dynamics of marginalization[27]. With regard to the second and third degrees, there were no follow up questions that could help to identify specific links and particular features of those degrees. This is particularly relevant for the third degree; usually participants refer to as *majnoon,* which implies a greater disconnection with the community.

4- Data Analysis:

a) Literature review

Two considerations have to be in mind with regard to the literature review. With regard to prevalence and forms of mental health disorders, data catches studies from 1988 up to 2009 and they do not always trace the same topic. The result is a mosaic of several mental health disorders that have grabbed the interest of academia along these years. There is no consistent data that measures mental health in Egypt. Only the Status of Young People in Egypt measured for the first time mental health among young people using Self-Reporting Questionnaire (SRQ-20), developed by the World Health Organization. With regard to stigma there was very little literature that focused on Egypt so global reviews were added.

Prevalence and Forms of Mental Health Disorders

In 2009, a national survey of prevalence of mental health disorders in Egypt, estimates this prevalence at 16,93% of the studied adult population (main problems were identified as mood disorders, anxiety disorders)[28], while a **2001 survey stated that 50% of Egyptian students show symptoms of having a mental health disorder.**[29] Some of the most common disorders among patients admitted to hospitals are depression, anxiety, schizophrenia, and substance abuse.[30] Mood disorders are the most prevalent cases in outpatient facilities, while **schizophrenia** is the most prevalent in **inpatient facilities and mental hospitals**[31]**.**

Depression was found in 11.4% of the urban population and 19.7% of the rural population, and major affective disorder in 1.9% of the urban population and 3.3% of the rural population.[32] Somatic symptoms foreground affective ones, with common symptoms including decreased libido, agitation, hypochondriasis, insomnia, and anorexia.[33]

[27] For this reasons and as a matter of time assigned to the consultancy, it was decided to include in this report only the interviews that had English and Arabic transcripts.
[28] (SYPE 2010)
[29] ("Mental Health Situation and Services in Egypt" 2015)
[30] (Endrawes, O'Brien, and Wilkes 2007)
[31] (WHO and Ministry of Health 2006)
[32] (Ahmed Okasha 2004)
[33] (ibid)

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Anxiety disorders comprised approximately 22.6% of diagnoses made in a psychiatric outpatient clinic in 1993.[34] The most common symptoms of anxiety are worrying (82%), irritability (73%), free-floating anxiety (70%), depressed mood (65%), tiredness (64%), restlessness (63%), and anergia and retardation (61%).[35] Patients also suffer from panic attacks, situational anxiety, phobias, and avoidance.[36]

Schizophrenia is the most prevalent chronic psychosis in Egypt and affects the majority of in-patient cases in mental hospitals.[37] Delusions are often persecutory, religious, political, scientific, and/or sexual; catatonic forms of schizophrenia are the most common.[38]

Though there is a lack of data on **drug misuse in Egypt,** there has been a rise in the number of addicts seeking psychiatric treatment, drug-related health issues, and in adolescent addiction.[39] The most commonly used drugs in the 1980s were opium, cannabis, hypno-sedatives, cocaine, and heroin.[40]

Hysteria, or conversion and dissociative disorder, is also one of the top psychiatric diagnoses. A 1990 study of patients at the Institute of Psychiatry of Ain Shams University found a 5% prevalence of the disorder.[41] Many disorders that previously would have been labelled as hysteria now fall under different diagnostic categories.[42] This, in combination with the changes brought by industrialization, has led to a drop in diagnoses of hysteria.[43]

Children, adolescents, and the elderly are also significantly impacted by mental health disorders. In 1988, 4.5% of Egyptian elderly were found to have dementia and 2.2% Alzheimer's.[44] A 1999 survey found that 59% of Egyptian children and adolescents experienced feelings of fear or anxiety, while a 1989 study of school students in Alexandria found that 10.3% showed depressive scores.[45] In 1990, behaviour disorders were found to comprise 8.2% of diagnoses of children in out-patient psychiatric facilities of the Ain Shams University hospitals.[46] In 1999, 42.8% of elementary school students were found to be scholastically underachieving, experiencing disorders such as depression, anxiety, attention-deficit hyperactivity disorder, speech difficulties, and elimination problems.[47]

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[34] ((ibid)
[35] ((ibid)
[36] ((ibid)
[37] ((ibid)
[38] ((ibid
[39] ((ibid)
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[41] ((ibid)
[42] (Ahmed Okasha 2004)
[43] (ibid)
[44] ("Mental Health Situation and Services in Egypt" 2015)
[45] (Ahmed Okasha 2004)
[46] (ibid)
[47] (ibid)

Defining, Assessing and Reducing Stigma

The roots of the stigma around mental illness are complex. One major factor in the stigma against individuals with serious mental illness is the belief that these individuals are dangerous, violent, or unpredictable.[48] Stigma is further perpetuated by negative media depictions and attitudes of doctors, as well as by the ways in which mental illness is associated with fear and danger in public perception.[49] The form of mental illness affects the intensity of stigma—for instance, depression is less stigmatized than schizophrenia.[50]

Stigma is defined in different ways, but the literature generally agrees that stigma: 1) differentiates individuals in a way that negatively impacts their social status 2) involves a power imbalance between stigmatizing and stigmatized individuals and 3) occurs in the two forms of public stigma and self-stigma. Link et al. define stigma as "the co-occurrence of its components–labeling, stereotyping, separation, status loss, and discrimination," while Modgill et al. identify sub-components of stigma as including perceived stigma, self-stigma, social distance, danger/violence, helping, negativism, and emotional reactions.[51] Link et al. also claim that stigma can only occur through a power differential between the oppressor and the stigmatized.[52] The USAID POLICY Project affirm this emphasis on power, framing stigma as a social process that produces networks of power and control and reifies social exclusion by naturalizing social inequalities.[53] Finally, stigma is divided into two categories: 1) public stigma, defined as prejudice and discrimination by society and 2) self-stigma, defined as the damage that occurs when an individual internalizes these social effects.[54] Effects of stigma include shame, distress, social withdrawal, lowered self-esteem and self-confidence, and increased negative affect.[55] These feelings can prevent individuals from seeking treatment and lead them to engage in negative interactions with other members of society.[56]

At present, there are significant issues that remain to be addressed in the **assessment of stigma around mental illness**. Available assessments are not easy or reliable to use in healthcare settings across countries or as means for routine monitoring.[57] Most assessments have measured discriminatory attitudes rather than behaviors and focus on medical staff to the exclusion of the administrators and non-medical staff.[58] **The feelings of the stigmatized remain understudied**, though a 2002 report by Link et al. showed that the primary feelings included the sense of being misunderstood, different, and/or ashamed.[59]

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[48] (Couture and Penn 2003)
[49] (Pinfold et al. 2005)
[50] (Collins et al. 2012)
[51] (Link and Phelan 2001; Modgill et al. 2014)
[52] (Link and Phelan 2001)
[53] (POLICY Project et al. 2003)
54 (Corrigan et al. 2012; Stier and Hinshaw 2007)
55 (Collins et al. 2012; Stier and Hinshaw 2007)
56 (Collins et al. 2012)
57 (Nyblade et al. 2013)
58 (Nyblade et al. 2013; Link et al. 2004)
59 (Link et al. 2004)

There was a dearth of experimentation studies and many of the concepts and instruments employed were Western.[60]

In a literature review of 123 articles published between 1995 and 2003, one of the **most popular stigma measures was social distance**.[61] Social distance is defined as the likelihood of an individual rejecting a hypothetical other with a stigmatized label, with greater social distance being correlated to higher stigma.[62] The majority of these studies demonstrated that people who were older, less educated, or who had never known a person with mental illness were more likely to want social distance from the mentally ill.[63]

In a 2005 study on social distance, **Coker argues that stigma in Egypt is associated more with whether the individual is able to perform his/her social role and less with fear of the individual.** Coker claims that stigma in Arab or Northern Mediterranean cultures has to do primarily with the ways in which the mentally ill individual relates to society, specifically in terms of possible negative impact and ability to fulfil his/her social role.[64] In the study, social distance was associated, from highest to lowest, with alcohol abuse, psychosis, possession, and depression and two-thirds of participants named social support as the most effective treatment for mental illness.[65] Some mental illnesses were viewed as deriving from societal pressures and treatable through social support, while others (such as "madness" or *majnoon*) were not seen as social were therefore more stigmatized.[66]

As per reducing stigma, research has suggested the positive impact of stigma and discrimination reduction (SDR) initiatives but has not demonstrated that these interventions lead to long-lasting impact on the lives of people with mental illness or on society.[67] In general, more research is needed on the effects of SDR initiatives on a wider range of outcomes (nondiscriminatory policy, increases in treatment-seeking, etc.), the effects of broad-based SDR programs, and the long-term effects on SDR initiative participants.[68]

SDR initiatives are generally aimed at changing the ways in which stigmatizing individuals perceive and act towards individuals with mental illness. A 1999 study by Corrigan argued that individuals who thought of mentally ill people as less blameworthy were more likely to act in helpful ways towards them (by fighting negative images, etc.) and that contact with the mentally ill led to a decrease in the perception of them as dangerous.[69] 5iple initiatives have proceeded from these claims, with the three primary approaches

60 (Link et al. 2004)
61 (Link et al. 2004)
62 (Coker 2005b)
63 (Link et al. 2004)
64 (Link et al. 2004)
65 (Link et al. 2004)
66 (Link et al. 2004)
67 (Collins et al. 2012)
68 (Collins et al. 2012)
69 (Link et al. 2004)

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being education, contact, and protest/social activism.[70] Of these three, contact (interpersonal interaction between the public and individuals with mental illness) seems to have the most potential in relation to people suffering from serious mental illness.[71]

In order for anti-stigma efforts to succeed, literature suggests that efforts must be multifaceted, multilevel, and address the attitudes and beliefs that drive stigma.[72] Corrigan claims that mental illness stigma reduction is most effective when 1) targeted toward particular populations or subgroups 2) locally based and delivered and 3) continuous, credible, and involving contact with individuals who have experienced mental health issues (TLC3).[73] Collins et al. argue that stigma reduction efforts should operate at the level of individual, social, and policy change to be most effective.[74] The involvement of mental health consumers (people with mental health problems) in anti-stigma interventions can also empower these individuals and reduce stigma.[75]

b) Desk review

To the literature review above, the desk review added reference to two fundamental aspects, first, an overview of people living with HIV and their particular stigma's circumstances. Second, the particular barriers that primary health care system faces in order to integrate mental health services.

For the first matter, it was included a desk review of the National Aids Programme reports. Although the prevalence of HIV is less than 0.02%, there are specific populations with much higher prevalence rates. People living with HIV were estimated to be around 11,000 with a high concentration on MSM and People Who Inject Drugs (PWID). In 2010 the MoH reported that 66.8% of HIV transmissions occurred through sexual activity. Among those whose transmission occurred through sexual activity, 46.2% of transmissions took place through heterosexual activity. Homosexual activity was responsible for 20.6% of transmissions. Transmission via injecting drug use represents approximately 28.3% of detected cases. Detected cases in children represented 4.9% of transmissions, possibly due to mother to child transmission. All respondents reported low condom use. Only 3% of respondents reported condom use with non-regular, non-commercial sex partners. Third, respondents in Cairo and Alexandria reported frequent commercial sexual activity. Specifically, 13.1% of PWID respondents in Cairo and 10.8% in Alexandria reported exchanging sex for money. Street children showed a low prevalence of HIV (0.5%).[76]

One of the principal remarks surrounding stigma was the low level of disclosure in fear of external discrimination, which was accompanied by high levels of

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70 (Corrigan et al. 2012)
71 (Couture and Penn 2003)
72 (Pinfold et al. 2005)
73 (Collins et al. 2012)
74 (ibid)
75 (Pinfold et al. 2003)
76 (NAP - Egypt 2016)

internal discrimination.[77] **Effective measures to tackle stigma pointed at effective participation of PLHA in the advocacy work.**

Direct stigma accounts of PLHA have recorded that PLHA can be denied of medical care, housing, employment, insurance, entry in the country, and their families and friends often abandon them and spouses file for divorce. The Egyptian anti-stigma forum, which counted with a thorough selection of experts and PLHA individuals, conducted a study focusing on stigma in different areas: health care sector, media, the Egyptian government, workplace, and family and community[78]. These areas helped to seed light into the many right's violations that PLHA suffer every day. The forum made important remarks[79]:

- Self-stigmatization and self-isolation are as damaging as stigma and discrimination.
- Accounts highlighted the idea that community look at them as deviants, with unorthodox or abnormal lifestyles or homosexuals.
- Support groups are a great source of comfort
- Healthcare system often incurs into the denial of care, breach of confidentiality, non-consensual testing, poor quality of care and gossip and blame.
- Good training of healthcare providers has gotten positive changes, as it has also done anti-stigma policies.
- The Media in general thinks that it is a topic of minor interest of Egyptians but when referred it is often using stigmatizing vocabulary
- Print media tents to sensationalize, criminalize and attribute immoral behaviours to PLHA
- TV send the message that is a disease afflicting drug users, MSM, promiscuous men who sleep with foreign woman or sex workers[80]
- There is a high concern on the role of media, as it is the source of general knowledge for the broad population.
- The government directly stigmatize PLHA as the may be denied or visa entries, which is a great concern given the current wave of refugees and Egyptian police conduct mandatory testing on people who have been arrested and are suspected of being-HIV
- Stigma in the workplace is very high
- Family and community can be the first foster of stigma and discrimination with a great gender bias that tent to forgive easier men and hold responsible women for the infection. In general, there is very poor knowledge about HIV/AIDS, communities tend to think that the PLHA has done something immoral
- Religious leaders could be a key stakeholder to spread and gain support for PLHA, however there is very little studies on the matter.
- Referral is still one of the greatest problems.

As per the question to access to mental health services, there was very little data available to assess potential shortfalls, challenges, and resources. However, in

[77] (ibid)
[78] (Ford Foundation 2016)
79 (Ibid)
[80] (UNWOMAN 2007)

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2009 UNFPA conducted a study about the impact of the health sector reform on reproductive health services in primary health care units.[81] The study looked into policy environment, resources, political support, client satisfaction, etc. Some of the conclusions of the study could be use as guiding questions to assess the situation of mental health care services in primary health care units. Here there is a collection of the most relevant ones, but a careful look into the document when developing questionnaires for health practitioners is highly recommended. Some of the relevant questions to take into consideration for mental health interventions are:

- Is there an explicit support for mental health programmes or is it implicit in boarder policies?
- Is there an updated document with goals target and strategies?
- Primary Health Units are promoting the figure of family physicians who can come from many different backgrounds. Egyptian clients in the study were found to prefer specialised physicians, would that also be a problem or clients seeking mental health services?
- MoH has historically suffered from the impact of extreme vertical and centralized programmes; which are the roles of the MOH and different instances with regard to introduction of Mental Health Care? Who has to be involved?
- Which are the services that PHCC should provide?
- Is the environment at the MoH supportive of mental health programmes?
- PHC units suffered from a high turnover of physicians, therefore it is essential that mental health is part of the pre-training service, is it included?
- Which is the job description of the family physician and how is mental health included?
- Physicians are severely involved in paper work with very little time for clients, how this will impact the quality of the service provided?
- Is physical infrastructure of PHC adequate to provide mental health services?
- Is the community aware of the concept of mental health?
- What is the outreach programme and who is involved?
- How are the rights of the patients protected?
- How is PHC units' protocol of referrals?

Finally, particular problems of access may arise when focusing on services provided by NGOs. For this scenario, NGOs should be assessed one by one with specific tailored tools for the purpose.

c) Interviews with children living in street situation

The questionnaire start by asking interviewees if they can identify what is mental health and what causes it. Family violence, explained as troubles at home, dad or mom shouting and treating the children badly, -including physical and verbal punishment-, violence from siblings and pressure from other relatives is the main source present causing 'tiredness' or 'bad mood' which is the lexicon used by the interviewer to refer to negative mental health status. Absence of the

[81] (El Zanaty 2016)

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mother or the father is also very present as a source of pain and children often referred to the idea of regaining their families as the solution for their mental health problems. Anything related to an event that includes them in a positive way, like a festivity, a join activity, or receiving their visit to the centre, is a cause of happiness.

Divorce, death of any of the parents, economic problems, addictions and imprisonment are some of the conditions expressed by the children referring to the situation of their parents. Often they recognise in their parents the 'tiredness' that later on apply to themselves**. Absence of parenthood care and violence are elements often interlinked in self-nourishing relationship, as the former deteriorates, the latter becomes more prevalent**. This seems to be the main source leading to children getting disengaged from educational outlets, inconsistence in their learning, and getting more acquitted to the street.

There is also some reference of violence exerted from peers in the street. However, 'going out' which often means going to the street is perceived as a coping mechanism. They also expressed a positive feeling about the shelter and the support of the therapists and in general interviewees paid great importance to their own school performance or the lack of it when they do not feel well.

The questionnaire differentiates between first –referring to the children-, second –referring to close relatives- and third –referring to someone in the community- degree of people that suffer any form of mental health problem. It also introduces the difference between 'mental problems' and 'mental illnesses'**. With this regard, children tent to refer as 'mental problems' their condition and the condition of the second degree, whereas 'illness' is often used to refer to someone of the third degree that shows much worst and deteriorated condition to theirs.** It is only to this third degree that they use the lexicon *majoon,* which is translated as crazy. **The way they refer to them signals that that person is not considered as part of the community's participant.**

With regard to healing, 'having a mental problem' refers to the concrete source that creates them, hence they believe their problems can be solved. Talking to someone that they trust –relatives and specialists- is constant as one of the most important tools to help them during this period. However, when talking about 'having a mental illness', children tent to mention God or religion to heal that person, implying that it cannot be cured. It is acknowledged that specialised doctors can help, however interviewed children; instead of mentioning the centres or the shelters were they are, often refer to the hospital as the place to treat that person. In most of the respondents there is a degree of empathy with these three cases, children may fear them, but they also feel pity for them and in some cases they have help them when they were lost, or other children were throwing rocks at them. Some interviewees have mentioned some differences in terms of age of the person of concern when it comes to people living with them in the centres. Gender was only mentioned when referring to the third degree. It seems they will be more prompt to help and be less scared of a woman that of a man.

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Interviewed children have talked about feeling sad, isolated, anxious, suffocated, afraid, stressed, and tired. Crying, running away to empty spaces, stop eating and drinking are mentioned as first-degree responses when someone is upsetting them. They also seek playing, running, an excuse to laugh and for someone to talk to cope with bad feelings.

Being in the centre/ shelter and attending therapy or having a counsellor has got a positive effect towards understanding what psychologists can do for them, which can be understood that it also helps to cope with the stigma associated to children leaving in street situation.

Finally, it is not clear how children got to the centres, however some of them have mentioned that they left their homes, or that the prosecutor order it after a trial that they took part on, or their families left them there. **It was noticed a great ambivalence towards how to refer to that episode with regard to feelings of guiltiness and responsibility.** Some children have narrated this moment as a moment of courage, which they feel proud of, thinking that it was an empowering reaction towards an unsustainable situation. However the current feelings of missing their families and abandonment makes them question their decision. In the same line, the street could have been a place to withdraw from home, until it turned a place where they are also abused. **In both cases children show a great degree of agency an awareness of their situation.**

d) NGOs' staff working with MARPS:

As per the observation of trainings, **the guiding note should register which are the positions of the participants in the NGO attending the training** and which is their relation to the clients: administrative, therapist, programme managers, social workers, etc. This is important because there were many notes referring to side talks that implied discriminatory practices and judgements. **This reveals staff's dynamics and prevailing working cultures that may prevent participants from expressing their opinion and doubts with no constrain at the same time that it perpetuates behaviours that can foster stigma**.

There was no mention to the particularities of the different locations used for the activities and trainings, except in two cases were noise was a serious constrain to carry out the proposed activity.

The interaction with MdM training staff has been noted ass friendly and positive. However, again some side talks and observations of staff conducting activities in their own NGOs revealed that **participants are aware of a certain MdM culture which may bias their responses** toward mitigating their own opinions and behaviours to adapt it to a more MdM-friendly narrative, which we understands it is more open than the prevailing cultures in their NGOs. **In this regard, it may be useful that researchers observe more activities carried by the NGOs with their clients.**

All the workshops were very interactive, including icebreakers that were useful to warm up the room. There were a great variety of activities that help to bust

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the energy in moments of lack of concentration or tiredness. It could be differentiated three kinds of training activities: a) clarifying/ providing technical information, b) narrating personal and professional experiences and c) decision-making and enacting scenarios. Research-wise, comments in activities a) and behaviours in activities c) provided a good insight of potential shortfalls in staff attitudes, whereas b) revealed more an accommodation towards what it is 'ought to be' or the MdM- politically correct answer. **Promoting more activities of type a) and c) is therefore recommended.**

As per if the trainers allowed participants to express their opinions, the many interactive activities should have helped to do so, however it seem that often groups were reproducing in the room social and community stereotypes related to each of the MARPS. In this regard, the programed activities were not effective enough to break peer and societal pressure. **A careful selection of participants and NGOs, and specific activities tailored for the purpose could help to break this tendency.**

Participants to a great extend seem interested in the workshops. Materials were in most of the cases received with no surprise or shock, except in one case were they seemed annoyed. **This can be a positive thing in terms of acceptance of the training; however testing the limits in some activities may be useful to reveal negative attitudes towards NGOs' clients.**

With regard to stigma related practices recorded in the field-notes, the main remark is that **participants tended to look at their work with MARPS assuming the same stigma's stereotypes that society has on these same issues.** There were some comments referring to opinions of relatives and friends about the participants' jobs with MARPs that revealed that **there is neither much understanding nor acceptance nor social consideration of their position**. Also, one interviewee complained about the low salary, which is another issue that families may take into consideration to judge people working with MARPs.

To further explain this point, it is useful to refer to the role-play activity carried out in some of the trainings. While language use was appropriate in most of the cases[82], **there was the common understanding that the issues they treat are very difficult –if not impossible- to solve, which condemns the client to social marginalization.** This stigmatizing believe was also reflected in the way the therapist in the role-play let the client –also in the role play- express their problems and sorrows, which was very limited.

There was another exercise that also showcased the same argument. Participants were asked to agree or disagree in a set of statements. One of them asked if it would be OK that their children become friends with other children that were formerly in street situation. **All participants, except one, agreed that they do not want their children to become friends with street children, or**

[82] There is only one record noting a direct stigmatization through language. A participant woman referred to mental health patients as 'maniacs' in a side talk.

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only if the children can *prove* that they have changed. It is not very clear what exactly do they mean by prove, however to *prove that change* is a highly problematic statement that fosters stigma and neglects the root causes that brought these children to the streets. It just assumes that they are bad kids with rare possibilities of rehabilitation. It seems that the prevailing feeling is that one of keeping their children *save* and coping with the *pity* coming from working with children in the street whose fate is to remain as they are. Also underpinning this reasoning, there were comments pointing at blaming the government as the sole responsible. **This can also be read as if the government is not responsible neither they will be. This argument is also problematic because it also reveals a poor understanding of duties and rights framework in the context of street children. To this regard it is important to say that as per the data received, there is not a single mention to human rights.**

Finally, **the participant that disagreed with his peers was known to have some background as a street child. As per the records shown, he found these comments very upsetting**. He uttered to his partner:

> *'Why do you work with them then?!'* (Referring to their doubts of the possibility of change) *'Some people should not be doing what they do'* and loudly added: *'why don't we treat each other similarly in vulnerable situations? The community will never change unless classism is over.'*

This statement enlightens two particular points referring to stigma already treated above: a) **understanding positions within the NGO and background of participants is essential to understand how far they will go against community stereotypes** in the training and in their own work, very easily participants will replicate community and government narratives; b) **NGOs workers that are in direct contact with the clients or share similar backgrounds or some features are greater advocators for change** and more promote to break peer pressure and societal stereotypes; therefore integrating them in the advocacy work is a recommended actions, as also the desk review has suggested.

The interviews with key staff working with children with special needs showed that stigma could be easily overcome when people do get in contact with the stigma-carrier. **This is to say, when they manage to build a link where they recognise each other in a certain relationship**. According to this, as a general conclusion and always keeping in mind that this finding will need further research, it can be concluded that **many of the participants of the trainings were not in direct contact with the target group of the training or were not familiar with MARPs' situation or did not have an emotional link built with this audience.** This point was also recorded in the notes of one of the ethnographers, which said that one participant said that a direct obstacle to apply the training was that they do not work directly with the clients.

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Finally, only one participant mentioned that the training was useful to realize which her own biases when working with MARPs were. As part of my own research I have noticed that it is quite common to look at trainings as 'scientific' knowledge where participants are provided with **technical** and **neutral** information. As far as this is useful to avoid cultural an even security barriers, it also carries the disadvantaged that they do not foster self-reflection exercises were participants can assess their own status, work, performance, engagement, biases, etc. It is rare to find these kind of exercises within the objectives of the training exposed during the first day, however, **it could be highly recommended to introduce self-assessment tools** (even if they are not shared later on with the MdM team) that look into personal development.

e) Stigma's stereotypes and related obstacles to overcome it

Although the methodology to collect data on stigma could be improved, there was some information related to stereotypes that could be extracted from the interviews and from the ethnography reports. This information would be useful to tailor specific questionnaires that address how participants perceive stigma and how staff reproduce it.

There was a clear gender bias in most of the comments. Women MARPs tent to be treated on high discriminatory basis. Several times the note '*women are controlled by their emotions rather than by their intellect*' appeared to justify certain positions regarding decisions making, which plays with the idea of a low exercise of women's agency. On the other hand, when confronted with cases of violence, rape or sex work, there was often the assumption that the woman had to be blamed, which plays with exactly the opposite idea: women have a high degree of exercising agency. In this sense, women that practice sex work are among the most stigmatized. The multi-layered reality of MARPS[83] is also gendered therefore. **This is to say that women sex workers that are also drug addicts, for instance, will be mainly perceived as sex workers, which carries a higher level of stigma and gender discrimination.** Some of the collected comments where: *'they have a choice'*, *'they do it for money'* or *'they could move somewhere else and have a fresh start.*' **Besides, the participants involved in this research mainly depicted sex workers as adults, although many street children often engage in sex work.** Again, multi-layered stigma processes may prioritize this view, which has the negative effect of a) rendering invisible the street children involved in sex work, or b) making it a taboo even for these organisations or c) showing that these participants are not familiar with this phenomenon. Also the language used in the training rooms when referring to sex workers was different. First because it provoked laughs and second because the use of derogatory language was more accepted. Finally, discussing same sex relationships was still a taboo.

Something present in the participants' comments and also well noted by other research is that talking about the body, particularly about women's bodies, is difficult, annoying and sometimes judged as not appropriate. In the same line talking about sex is even more discomforting. The only shared reflection on the

[83] This idea will be explained in the next section 5: Notes on Access and Stigma: Raising the problematic.

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issue was that body appearance played a great role in awareness campaigns. I interpret this as: **cleanliness, hygiene and certain features may help to find respectability from the community. Participants did not mention it in this way, so this is a point that may need further research**.

Children living in street situation are mainly perceived as cases that are difficult or impossible to solve. Staff working with them acknowledge that relatives sometimes ask them *how can they work with criminals, impossible to rehabilitate, an epidemic, etc*. which leads questions such as *why do you this to yourself?* Or *how can you manage something like this with you soft personality? Good bless you*. These statements may have also the interpretation of voicing their own fears through questions received by their families and explained as such during the training, which makes it more acceptable to say**. In the end, staff members are also part of a community and they carefully care about how to maintain their own reputation. Defending in public what society believes is a lost case or a criminal may seem risky, even more in the current situation of political dissonance and social turbulence.** Any of the participants believed that changing how we refer to them will be of any help. They believed soon the new label would carry the same connotations. Finally they also referred to them as '*a ticking bomb'* this term could be also a departing point for some research as it implies several considerations. First, it acknowledges the dynamic between the street children and their communities, which is an entry point to understand the genesis and hence the responsibilities of these groups with the community and the state. Secondly the reference to *time* may carry two assumptions: a) their condition are deteriorating so they will explode or need to be contained and b) these group is also aging, so they may not be children for much longer, hence they will become a real problem. **All these interpretations delve into the idea that there is nothing positive that can come out of them. Also the reference to potential criminal activities depicts a male children/ youth, which again shows a gender bias involved in stigma processes.**

Finally, **it is important to highlight that material conditions are rarely mentioned** although they may be the trigger of many of the unsustainable situations that leads NGOs' clients to become MARPs and cohabit with violence, emotional breakdowns, family troubles, etc., questionnaires should collect information on this aspect too. **Also experiences of MARPs clients to access the law and protection mechanisms are not collected**. Both angles will help to overcome the myth that street children, or sex workers are just bad people**. It will rather seed light into state and community dynamics that have failed to protect the rights of women and children.**

As per the potential obstacles that participants expressed they could face in order to implement the training, there were many comments regarding culture and religion. Participants often mentioned that there are certain emotions that can be important for healing processes but that are frequently censored by peer pressure. Crying for grief and superstitions were the given examples. It was interesting that participants also mentioned the negative role that the media plays in normalizing a negative image of MARPs and also normalizing certain

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drug use, such as alcohol and hashish. **It is important to consider that Media messages are also influencing them as much as they influence their communities, so missing positive messages in media foster by public figures also hampers their ability to defend and advocate for MARPs' cases.**

Finally, there was an interesting comment that related to Coker's notion of stigma[84]. Participants in one training agreed that to a certain extend Egyptians are able to *predict the bad things that will happen to them,* because they know how community will punish their misbehaviours. This comment referred to the great influence that community exercise on the individuals that compose them. In line with both, Coker and this statement, **stigma then could be measured by the different degrees that the community has exercise to isolated and punish a certain individual**. As an example, participants mentioned the importance of nicknames; this could easily be a question to be included in the interviews.

On the practical level, the main obstacles identified were lack of enough resources and lack of referrals to quality services for cases that cannot be attended in their premises. Also, as mentioned above the participants in the training were not in charge of dealing with clients directly. To this regard, trainings should spell clearly in the objectives which is the target audience and what it is expected form them.

5- Notes on Access and Stigma: Raising the problematic

The findings of this report have pointed at several specific dynamics that need to be beard in mind when designing advocacy and programme interventions. As explained by Coker (2005a) and also traced along the data, mental health disorders in Egypt are stigmatized according to their effect in threatening the social fabric. This is to say according to what extend the incumbent is able to perform his/her social role adequately. The main barrier to overcome stigma, as expressed by the interviewees, is that mental health disorders cannot be cured and as such services reflect this societal vision. In this context, access and stigma are concepts highly intertwined and in the same line, services available to heal and the social vision for rehabilitation are also highly linked. Having this background in mind, there are some dynamics that need to be unpacked:

a) In one hand, the literature review has shown that most of the psychiatric practice and the academic review is based on hospital based data which are cases that according to the questionnaire guideline will be labelled as third degree of mental health, the *majnoon*. This is the most severe case that society believes cannot be cured. On the other hand, the current development of mental health services is mainly happening under community and NGOs services or under the HIV programme in the MoH foster under the auspices of development projects. HIV and MARPS programmes alike, grants access to these services once individuals have come under the label of MARPS, which implies that communities (and programme documents as well) will signal these individuals as outcasts. **The combination of these two elements fosters a subjacent**

[84] (Coker 2005a)

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narrative that mental health services, as known by the communities, are available for people who cannot perform in society, hence have to be marginalized or punished or contained.

b) The interviews also asked about mental health 'problems' which usually referred to the cases that were not receiving treatment in the hospitals but rather therapy in the NGOs or shelters. These interviews also labelled individuals as a specific category of MARP (sex worker, person living with HIV, person with special needs, street children, etc.). This label as a specific category of MARP strips individuals from the societal features that keep them linked to the community to highlight his or her vulnerability (or the feature that condition his/her outcast). This is to say that the daily life reality of MARPs is that besides the assigned category, they are also many other things (mother, workers, students, poor, survivors of violence…), however the assigned category neglects the multi-layered reality of MARPs (and individuals in general). Multi-layer refers to the many features that compose one individual identity, which can be age, gender, education, occupation, place of residence, etc. besides her or his rarely one but many MARP conditions (they can be HIV carriers and being a child, abusing drugs, etc.). In parallel, NGOs workers were found to be operating under the basis of charity principles rather than under a -in most of the cases- rights' framework, hence they were not found to be challenging societal visions. **The combination of the development-imposed categorisation of MARPS along the charity based operational principles fosters sentiments of pity that prevent the reintegration of these individuals into society; neglects other more empowering features such as for instance survivors of violence, or individuals whose basic human rights have constantly being violated and, finally, also reproduces stigma.**

c) Expanding on the above idea, it is then necessary to acknowledge that also inside the MARP categories there are power dynamics that hierarchized differences. As it was explained in the case of the sex workers, different features will be highlighted or hidden accordingly.

In line with point a, b and c and with the literature review, it is then needed to re-conceptualize stigma as a relationship between a set of interrelated concepts: labeling, stereotyping, status loss and discrimination in the context of a power difference[85].

d) An (un)intended consequence of this labeling process is also that root causes as explained by NGOs (mainly violence and poverty) and the failure of protection mechanisms at the family, community and state level obtain less visibility (if any) which directly affect the deliver of services and access. **The co-responsibility framework that eventually could exert pressure to foster the need to maintain these individuals in the community is diluted and as a result individuals are to be blame for their own destiny.**

[85] (Link and Phelan 2015)

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e) Finally, marginalizing MARPS and containing services also marginalized the access of the broader population to mental health services. Therefore it is essential to understand which are the entry points and the entry subjects that could expand the understanding of what can communities in general expect from mental health services available to the general population. **Mainly this will link access to mental health services as part of public health policies.**

6- Conclusions and Recommendations

Based on the finding of this report, data collection methods could be improved with the following recommendations:

- **PHCU need to be included in the data collection methods** with specific tool tailored for the purpose
- **Questionnaires should be redesigned to address access and stigma in all the different stakeholders**: target groups, NGOs Staff, PHCU Staff, MoH, etc.
- Ethnographic report should **include the position of the people attending trainings**. Also, observations were much richer in seeding light into specific dynamics reproducing stigma when the researcher **collected critical quotes.**
- For the purpose of collecting data on barriers to access mental health services it will be very useful to **train data collectors on how to collect live stories.** This should be accompanied with training on ethics and data protection to preserve the rights of the people that would like to share their stories with MdM team. In this regard, a guiding note should be develop per target group.
- Focus group discussions with communities were not successful, this can be replaced by other methods such as **observation of how the partner NGOs engage with communities through their own trainings or community awareness raining campaign, etc**.
- The concept of **Social Distance** to determine stigma dynamics has come across the literature review and the data. **Therefore it is suggested to further introduce it in the development of new questionnaires** (social distance has been measured by asking participants if they would accept, would not accept or would accept after treatment the hypothetical person in four different situations: a friend, a family member by marriage, a teacher for a child and a neighbor.)[86]
- For research purposes, **activities in trainings that force participants to make decisions and enact role plays have been a source of good data since researchers have limited opportunities to observe interaction with clients.** It is recommended to particularly pay attention to promote these exercises in trainings and to facilitate researchers to observe them.

As per the findings according to the data reviewed:

- MARPS are **definitely the bearers of specific mental health problems related to their condition as MARPS**. What it is also very important is to highlight that along their specific mental health conditions, **there are also the similar root causes** that usually accompanies it**: violence from**

[86] Coker2005

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family and relatives, very poor economic conditions and failure of the protection systems (family, community and state)

- Also, the literature review has shown that there are larger groups, young people, children and women in great need of assistance. Keeping in mind the very particular economic, social and political events of the past five years**, it is essential to promote and advocate at the policy level for mental health policies that recognize the need of mental health services for general populations and not only for MARPS.**
- Strengthening services for MARPS' clients is different from strengthening services for general populations at the PHCU. Similarly, outreaching, referral and advocacy objectives. Therefore there should be different assessments that look into the integration of MARPS and General Population needs into the PHCU.
- Integration of services into PHCU will encounter historical problems such as: Egypt's lack of financial and human resources in the mental health care sector, especially in rural areas and lack of adequate community-based, preventative, or aftercare services or adequate collaboration between the health sector and civil society. For this reason, it is essential to understand the limitations and opportunities to further foster this initiatives. Key actions would be:
    - To identify key actors that need further support: MoH Central Governorates and pre-service training
    - Identify referral systems
- One effective way to reduce stigma among NGO workers highlighted in the desk review and in the data analysis **was to secure that NGOs staff are in contact and deal with the target groups on frequent basis and on positive instances.** In order to do so, successful practices have achieve good results when the NGO provided **spaces for the target groups to meet and organize their own activities** and when the **NGO facilitates support groups.**
- The main barrier (and assumption) encountered several times is that these cases cannot be rehabilitated. **Therefore Advocacy campaigns should clearly tackle the issue of healing and foster a vision of rehabilitation**.
- **Advocacy campaigns should carefully consider how to advocate for MARPS needs highlighting features that bring these communities close to their communities of origin**. Linking root causes such as violence and poverty to mental health could be a common denominator to find an element of unity.
- In the same line, there was a clear absence of human rights knowledge that was not targeted in the training. **Human Rights and Health could be an angle to explore for training and advocacy purposes.**
- **Selection of participants** for workshop taking into consideration their duties and positions in the MoH or NGOs is very important to trigger dynamics that will break taboos and hierarchies that reproduce stigma.
- Trainings should also have into consideration **self-development paths of the participants**, so there are specific exercises tailored to identify their own shortfall and misconceptions.

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- With regard to the last two points mentioned above, it is highly advise if NGO and MoH staff can select when and which trainings to attend according to what they think it is important to develop according to their duties. **Therefore, it is recommended a different methodology to select participants.**

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